

Project title: _____

SEER-MEDICARE DATA USE AGREEMENT

Information regarding persons with cancer is sensitive. Therefore, specific laws have been enacted to insure the confidentiality of individuals included in cancer registry data. In utilizing data on such individuals for research purposes, it is absolutely necessary to insure, to the extent possible, that uses of such data will be limited to research. Uses for any other reason, particularly those resulting in personal disclosures, will be prosecuted to the full extent of the law. In addition, release of information about the providers, i.e. the physicians and hospitals that provide care for cancer patients, may compromise the willingness of these providers to cooperate with the activities of the cancer registries. Therefore, considerations regarding the privacy of providers are also of great importance.

In order for the National Cancer Institute to provide the linked SEER-Surveillance, Epidemiology and End Results (SEER)-Medicare data to you, it is necessary that you agree to the following provisions:

1. You agree that the statements and methods made in your attached research proposal are complete and accurate.
2. You will not use the data for purposes other than described in your research proposal.
3. You will establish and maintain the appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it, as described in your proposal.
4. You will not permit others to use the data except as collaborators for the research as described in your proposal. Within your institution or organization, access to the SEER-Medicare data shall be limited to the minimum number of individuals necessary to achieve the purpose stated in your proposal.
5. If you move to a different institution, you will notify NCI in writing within 30 days regarding the disposition of the SEER-Medicare data. If you take the data with you, then you must provide NCI with updated contact information. If the data remain at the initial organization, then you must designate who is responsible for the files and insure that he/she signs a copy of this data use agreement.
6. You will not attempt to link nor permit others to link the SEER-Medicare data with individually identified records in another database without the written consent from the applicable SEER registries. .

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7. No one having access to the data will attempt to learn the identity of any persons with cancer in these data and/or their physicians or treating hospitals. In the event that you discover or are able to deduce the identity of a specific patient or provider, you agree that you will not attempt to contact these individuals or institutions.
8. No findings or information derived from the SEER-Medicare data may be released if such findings contain any combination of data elements that might allow the deduction of a patient's or providers' identity. In tables, cell sizes less than 5 (five) must be suppressed. You agree that NCI shall be the sole judge as to whether any finding derived from the SEER-Medicare data would, with reasonable effort, permit one to identify an individual or provider, or to deduce the identity of an individual or provider to a reasonable degree of certainty.
9. You agree to provide NCI with a copy of all manuscripts to be submitted for publication prior to submission. You further agree not to submit such findings to any third party until receiving NCI's approval to do so. NCI agrees to make a determination about approval and to notify the user within 4 weeks after receipt of any findings. NCI's review of the findings is for the sole purpose of assuring that data confidentiality is maintained and that individual patients and/or providers cannot be identified. NCI may withhold approval for publication only if it determines that the format in which data are presented may result in identification of individual patients and/or providers.
10. You agree that in the event NCI determines or has a reasonable belief that you have violated any terms of this agreement, NCI may request that you return the data and all derivative files to NCI. You understand that as a result of NCI's determination or reasonable belief that a violation of this agreement has taken place, NCI may refuse to release further SEER-Medicare data to you for a period of time to be determined by NCI.

Please indicate the SEER-Medicare files you are requesting:

_____ Patient Entitlement and Diagnosis Summary File) (PEDSF)	years requested _____
_____ Summarized Denominator File (SUMDENOM)	years requested _____
_____ MEDPAR	years requested _____
_____ Carrier (physician/supplier)	years requested _____
_____ Outpatient	years requested _____
_____ Home health agency	years requested _____
_____ Hospice	years requested _____
_____ Durable medical equipment	years requested _____

Are you seeking data for:

_____ Cancer cases _____ Non-cancer cases

_____ A proposal that describes the research question and analysis plan is attached.

Signature of Principal Investigator (In the case of students and fellows, the department chair or advisor from the student's academic institution must sign the data request)

Your signature indicates that you agree to comply with the above stated provisions. Deliberately making a false statement regarding any matter within the jurisdiction of any department or agency of the Federal Government violates 18 USC 1001 and is punishable by a fine up to \$10,000 or up to five years in prison.

(Name – printed or typed)

(Institution/Organization)

(Street Address)

(City/State/ZIP Code)

(Phone No. - Including Area Code and Fax No)

E-mail address

Signature

Date

Signature of Custodian of the Data (complete this if the data will be stored by someone other than the Principal Investigator)

Your signature indicates that you agree to comply with the above stated provisions. Deliberately making a false statement regarding any matter within the jurisdiction of any department or agency of the Federal Government violates 18 USC 1001 and is punishable by a fine up to \$10,000 or up to five years in prison.

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Date